



Guidelines for general practitioners when a baby dies suddenly and unexpectedly

These guidelines have been written to help general practitioners through a stressful and difficult time when they are called to deal with a baby who has died suddenly and unexpectedly. They should be read alongside FSID's guidelines for the other professionals involved in responding to sudden infant deaths. You need to ensure these guidelines form a part of your PCT strategy.

If you are the first person contacted

1. Check the ambulance service and proceed immediately to the scene.
2. If in doubt, resuscitation should always be attempted and continued en route to hospital.
3. If it is quite clear that the baby is dead and cannot be resuscitated it is best to inform the parents sympathetically.
4. If the baby is dead, you may confirm death in the home or you can leave this to the hospital. In all cases the baby should be taken to the hospital casualty department, not straight to the mortuary, where immediate examination and investigation can be done.
5. Take a brief immediate history from the carers and record the circumstances of the death (e.g. position when found, bedding, vomit etc.). Your notes will be very helpful to the paediatrician who investigates the death.
6. Spend time listening to the parents. Mention the baby by name and don't be afraid to express your sorrow.
7. Contact the paediatrician designated for cot deaths (babies who die suddenly and unexpectedly) who may wish to see the baby and parents as soon as they get to the casualty department.
8. If the baby is a twin, suggest that the surviving twin should be admitted to hospital for observation.

If you learn later that a baby has died

1. Try to see the family as soon as possible. Parents greatly appreciate the contact and time taken
2. Discuss the legal position regarding the coroner or coroner's officer and the arrangements for registering the death. Explain that the police will have to visit and ask questions, and

that this does not imply suspicion of wrong –doing by the parents. Inform them that bedding and other items may be taken away.

3. Discuss the need and legal requirement for a post mortem examination. Reassure the parents that their baby will look presentable afterwards.
4. Mention that some funeral directors make no charge. Mention that it may be possible to claim a Funeral Payment. Advise that the child benefit book will need to be returned.
5. Offer to attend the funeral (if you can).
6. Encourage the taking of photographs, and other mementoes i.e. lock of hair, hand and foot prints.
7. Contact relatives or friends. Make sure the parents get home from hospital and that they are not left alone.
8. Discuss the care of siblings; explain the need to involve them according to their age.
9. Check whether spiritual help is required, and arrange appropriate contacts.
10. Liaise with other members of the practice, especially the health visitor midwife (if involved).
11. Let parents know about FSID's Helpline (0870 787 0554). A free phonecard is available to parents whose baby has died so that they can call the Helpline free of charge.
12. If mother is breastfeeding discuss methods of suppression of lactation.
13. Spend time listening to parents and ask them to tell you what happened.
14. Ask them about reactions of siblings; tell them how they can get advice if they need it.
15. Give them a copy of FSID's booklet 'When a baby dies suddenly and unexpectedly'.

Further measures

1. Inform the paediatrician designated for cot death as soon as possible. If there is no designated paediatrician then inform the community paediatrician.
2. Attend a case discussion that should be held about a month after the death. The other main participants are the paediatrician, health visitor and pathologist who did the post mortem examination. The primary care team are essential participants so give it a high priority (you can ask that it is held at a time to suit you). The purpose is to discuss all aspects of the death, including possible causes or contributing factors to see what lessons can be learnt and to plan support for the family.
3. Inform the Child Health Department so no further computer generated appointments for immunisation or developmental checks are sent out. Also inform the hospital medical records department to ensure no further clinic appointments are sent.

4. Discuss with the designated paediatrician who should visit the family to explain the findings of the post mortem examination.
5. In liaison with the health visitor revisit the family as frequently as seems appropriate to offer support, answer questions and to check on the welfare of other siblings. Leave enough time for the contact to be meaningful.
6. You don't have to know all the answers. Be prepared to say "I don't know". Although we know some of the reasons why babies die suddenly and unexpectedly, much is still to be understood.
7. Remember that members of the wider family may also be grieving.
8. Ask if the parents would like to be put in touch with an FSID befriender, or other voluntary support.
9. Tell them they are welcome to contact you at any time.
10. Please ensure that all parents are given a copy of the DOH's leaflet 'A guide to the post mortem examination procedure involving a baby or child' (reference 29768/A) and that the content is discussed. Every parent should be given the opportunity to donate tissue for research, education and audit. Please ensure that the consent form for parents 'Post mortem examination on a baby or child ordered by the coroner' (reference 29773) is explained. Don't assume that someone else has already discussed the post mortem and tissue retention with the family. Always check with the parents. The leaflets are available to download from www.dh.gov.uk

Longer term contact and future plans

1. Remember anniversaries and make appropriate contact
2. Discuss the possibility of future pregnancies advising that it is usually best to allow time first for grieving for the baby who died.
3. Discuss the Care of the Next Infant (CONI) scheme.

Support for doctors

1. Call FSID's Helpline if you have any concerns or queries. They are there to advise and support professionals as well as families.
2. Partners, health visitors and others may also support you.

NB Some of these points may have been covered by other health professionals but don't assume that they have.

Some fundamental rules:

- Do not use technical terms or jargon. When you give families information check to see it has been understood
- Do not say things like:
"You can always have another"
"He was so young you hardly got to know him"

“At least you have other children”

“You’ll soon get over it”

“You will never get over it”

For further advice and support on responding to sudden and unexpected infant deaths call FSID’s Helpline on 0870 787 0554 or email support@sids.org.uk

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